Imagining future people in biomedical law

van Beers, B.C.

published in
Risk and the regulation of uncertainty in international law
2017

document version
Publisher's PDF, also known as Version of record

document license
Other

7

Imagining Future People in Biomedical Law

From Technological Utopias to Legal Dystopias within the Regulation of Human Genetic Modification Technologies

Britta van Beers

7.1 Introduction: The Rise of Utopian Technologies

Emerging technologies such as medical biotechnology, artificial intelligence, and cognitive sciences, have elicited wild speculation about, and vivid imageries of, the future of mankind, even beyond the realm of fantasy novels and science-fiction movies. Apparently, the fact that human beings are becoming the object of far-reaching technological interventions and inventions is to many a development of such an unprecedented nature that new images and vocabularies are invoked to describe both the hopes and the fears that these technologies engender. Charged expressions such as 'taking evolution into our own hands', 'playing God', and 'the Promethean drive to mastery', are a commonplace in these discussions.

Among scientists, prophetic statements about humanity's future can also be heard. A recent example is Stephen Hawking's much discussed proclamation that 'the development of full artificial intelligence could spell the end of the human race'. Even if existing forms of artificial intelligence enable the heavily paralysed theoretical physicist to communicate, he is concerned that in the future a more evolved type of artificial intelligence 'would take off on its own, and re-design itself at an ever increasing rate'. Hawking fears that 'humans, who are limited by slow biological evolution, couldn't compete, and would be superseded'.[1]

Where Hawking's warnings go back to a bleak and dystopian imagination of the future, other scientists' speculations on artificial intelligence are overtly utopian. For example, computer scientist Raymond Kurzweil predicts that a coming artificial 'intelligence explosion' will allow humans to transcend their biological natures, overcoming the limitations and fragilities of their bodies and brains.[2] Kurzweil is

[1] R Cellan-Jones, 'Stephen Hawking Warns Artificial Intelligence Could End Mankind', *BBC News*, 2 December 2014 <http://www.bbc.com/news/technology-30290540> accessed 18 April 2015.

[2] R Kurzweil, *The Singularity is Near: When Humans Transcend Biology* (Penguin 2006).

Imagining Future People in Biomedical Law: From Technological Utopias to Legal Dystopias within the Regulation of Human Genetic Modification Technologies Britta van Beers.

not alone in his techno-optimism. Other, equally 'transhumanist' scientists believe, for example, that a combination of artificial intelligence, regenerative medicine,[3] and cryogenic preservation[4] will allow them to attain immortality within their current life times. As French philosopher of science Dominique Lecourt aptly states, these hopes of human transcendence through technological means border on religious faith; the transhumanist project can be described as a form of *techno-theology*.[5]

In a way, it should not surprise anyone that even scientists are caught fantasizing out loud. The classic view of scientific practice, according to which scientists reveal and analyse the 'cold' facts of nature, is no longer tenable—if it ever was—as scientists are openly *engineering* nature within these new, technological contexts. Indeed, Kurzweil's dreams and prophesies illustrate how emerging technologies not only give rise to utopian narratives, but are often based themselves on utopian motives. They are, in essence, 'utopian technologies',[6] to use a phrase coined by philosopher of science Hans Jonas, who explains these technologies' utopian nature as follows:

> By the kind and size of its snowballing effects, technological power propels us into goals of a type that was formerly the preserve of Utopias…. The one thing we can really know of them is their extremism as such—that they concern the total condition of nature on our globe and the very kind of creatures that shall, or shall not, populate it.[7]

Moreover, since contemporary scientific practice heavily depends on financial investments from third parties, investors' personal imaginations of the future are also increasingly influencing technological developments. Recent statements by well-known billionaire Silicon Valley entrepreneurs Elon Musk and Peter Thiel offer striking illustrations of that tendency. Musk's quest to make space travel routine and affordable for everyone goes back to his dream to make humans 'a multiplanetary species'. The science-fiction novel *Foundation* by Isaac Asimov serves as his main source of inspiration.[8] Thiel, in his turn, invests large sums of money into the construction of artificial islands where people can live according to libertarian ideas. Ayn Rand's capitalistic utopia *Atlas Shrugged* serves as the guiding light to his project.[9]

[3] Eg, A de Grey, a well-known scientist in the field of regenerative medicine, believes that the first persons to become 150 years or older have already been born. See, K Kelland, 'Who Wants to Live Forever? Scientist Sees Aging Cured', *Reuters*, 4 July 2011 <http://www.reuters.com/article/2011/07/04/us-ageing-cure-idUSTRE7632ID20110704> accessed 19 April 2015.

[4] Eg, several prominent members of the Oxford Future of Humanity Institute will have their heads frozen after death in the hope that someday they can be brought back to life. See J Leake, 'Freeze a Jolly Good Fellow: Three Oxford Dons are Paying to be Cryonically Preserved', *Sunday Times*, 9 June 2013 <http://www.thesundaytimes.co.uk/sto/news/uk_news/Education/article1271389.ece> accessed 19 April 2015.

[5] D Lecourt, *Humain, Posthumain. La Technique et la Vie* (Presses Universitaires de France 2003) 12.

[6] H Jonas, *The Imperative of Responsibility: In Search of an Ethics for the Technological Age* (University of Chicago Press 1985) 21–22, 42.

[7] ibid, 21.

[8] R Carroll, 'Elon Musk's Mission to Mars', *The Guardian*, 17 July 2013 <http://www.theguardian.com/technology/2013/jul/17/elon-musk-mission-mars-spacex> accessed 9 May 2015.

[9] 'Floating Cities: PayPal Billionaire Plans to Build a Whole New Libertarian Colony Off the Coast of San Francisco', *Daily Mail*, 25 August 2011 <http://www.dailymail.co.uk/news/article-2024761/Atlas-Shrugged-Silicon-Valley-billionaire-reveals-plan-launch-floating-start-country-coast-San-Francisco.html#ixzz3ZdeRPWgF> accessed 9 May 2015.

Some of these technologies are now also targeting human nature itself as an object of change. These so-called human enhancement technologies, which aim to improve human evolution or to redirect the human condition, open up the possibility of turning certain visions of the human, or the post- or trans-human, into reality. Especially within the field of assisted reproductive technologies (ARTs), the once science-fiction scenarios of genetically designed human beings are on the verge of becoming a reality.

Tellingly, in a period of less than two decades, many of the technologies to select and engineer children before birth, which were depicted, albeit in a negative way, in the 1997 science-fiction movie *Gattaca,* have become, or are about to become, available. Pre-implantation genetic diagnosis, for example, has facilitated genetic selection of embryos since the 1990s; in 2012, prenatal whole genome sequencing was used to map an embryo's entire genome for the first time;[10] and in 2015 it was announced that a new technology, known as 'human gene-editing', will soon make it possible to modify the embryo's genetic constitution.[11] The technology of human gene-editing will be further explained below, as it will be used as a recurring example to illustrate the main arguments of this chapter.

As these rapid developments in the field of assisted reproduction make abundantly clear, technological projects of human *autopoiesis* necessitate reflection on the question of what makes humans human in the first place. In the words of the German philosopher Jürgen Habermas, 'whether these speculations are manifestations of a feverish imagination or serious prediction, an expression of displaced eschatological needs or a new variety of science-fiction science', they are all 'examples of an instrumentalisation of human nature initiating a change in the ethical self-understanding of the species'.[12]

Interestingly, to regulate these utopian technologies, a legal field has emerged which equally relies on future scenarios, fictions, imaginations, and symbolizations of the human. However, as will become clear, the legal imaginations of the future in this field tend to be more dystopian in nature.

In this chapter, I explore and analyse the ways in which imaginings of the future of mankind, and mankind itself, have found their way into international legal regulation of biomedical technologies. As will be shown, the use of different types of legal fictions to represent the human is one of the primary ways within international biomedical law, also called *biolaw*, to deal with the uncertainties caused by these emerging technologies. Moreover, as the texts of several international conventions and declarations in biomedical law indicate, one of the main aims of international biolaw is to protect no less than the future interests of humankind.

The increasing recognition of the importance of imagination for both the development and international regulation of biomedical technologies can be illustrated by a 2015 international summit on biotechnology: *Biotechnology*

[10] HC Fan, W Gu, J Wang et al, 'Non-Invasive Prenatal Measurement of the Fetal Genome' (2012) 487 *Nature* 320.

[11] For more on this, see section 7.2.1.

[12] J Habermas, *The Future of Human Nature* (Polity Press 2003) 42.

and the Ethical Imagination: A Global Summit (BEINGS 2015). This meeting was organized in the spirit of the famous 1975 Asilomar Conference, which brought together biomedical experts to develop guidelines in reaction to the then recently established moratorium on DNA recombinant technologies. What makes BEINGS 2015 of interest for this chapter is that all speakers and participants were explicitly invited to 'reimagine the aspirations of biotechnology'[13] in order to contribute to the development of international guidelines. For that purpose, prominent biomedical scientists were brought together with policy makers, corporate partners, and scholars from varying backgrounds, ranging from literature to religion. Tellingly, one of the keynote speakers was Margaret Atwood, novelist of critically acclaimed dystopian novels on biomedical technology, such as *Oryx and Crake*.[14]

This chapter discusses the importance of imagination for legal and ethical frameworks in the field of the biosciences. It builds on German–American phenomenological philosopher Hans Jonas's reflections on the emergence of technological risks for humanity, as developed in his influential work, *The Imperative of Responsibility.*[15] The chapter's main argument is that Jonas's thoughts can explain three important characteristics of international biolaw: its reliance on dystopian rather than utopian scenarios (section 7.2); the metaphysical nature of the view of humanity on which international biolaw relies to protect against future risks and uncertainties (section 7.3); and finally, the use of imagination and fiction in this legal field (section 7.4). Throughout this chapter, these points will be illustrated by recent debates on the international ban on human germline genetic engineering. This prohibition, which is at the heart of international biolaw, is currently being questioned, as recent scientific breakthroughs in the field of gene-editing are about to turn human genetic engineering into a reality.

7.2 Human Genetic Modification: Between Technological Utopia and Legal Dystopia

7.2.1 The rise of human genetic modification technologies

As the technology of human germline modification is currently making the transition from science fiction to actual science, and is generating much debate on its risks and dangers, it offers the perfect case to examine how possible futures and future people are imagined within biomedical regulation. Human germline modification involves making changes to the human genome that are passed on to future generations. Although human genetic engineering was not technologically possible until recently, it has been prohibited in international law documents since the 1990s. A prime example is Article 13 of the Council of Europe's Convention

[13] See the summit's site <http://www.beings2015.org/about.html> accessed 11 June 2015.
[14] M Atwood, *Oryx and Crake* (McClelland and Stewart 2003).
[15] Jonas, *The Imperative of Responsibility* (n 6).

of Human Rights and Biomedicine,[16] which states that 'an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants'. In 1997, when the Convention came into force, this provision was based on mere speculation. In early 2015, however, the significance of Article 13 was revitalized when two technologies in the field of human genetic germline modification made international headlines: mitochondrial replacement and human gene-editing.

In February 2015, the United Kingdom became the first state worldwide to legalize mitochondrial replacement.[17] The aim of this technology is to prevent the transmission of mitochondrial diseases to children-to-be. It involves enucleating an egg cell of a third party, and filling it with the nucleus of an egg cell from the prospective mother. This special egg cell is subsequently fertilized with the sperm of the prospective father. The resulting embryo is popularly known as a 'three parent embryo', as the child will be genetically related to two women and one man. Moreover, the technology could be said to constitute a form of germline genetic modification as described in Article 13, because the genetic alterations will be passed on to future generations. Nevertheless, as the intervention affects only mitochondrial DNA, and the nucleus remains unaffected, this technology establishes only minor heritable changes to the germline. Advocates of this technology therefore state that it is far-fetched to speak of designer babies in this context.[18]

This seems much less the case for the second biogenetic technology, which has been the subject of vigorous debates since the beginning of 2015. Several leading scientific journals[19] announced in March 2015 that a remarkably simple and cheap genome engineering method, called CRISPR-Cas9, was close to being successfully applied to human genomes. This 'gene-editing' technology allows scientists to 'cut and paste' DNA with extreme precision. According to the authors of said scientific articles, human gene-editing marks no less than 'the advent of a new era in biology and genetics'[20] as it brings the possibility of 'engineering the perfect baby'[21] within reach. Nevertheless, it is beyond doubt that this technology aims to realize interventions with the human genome that are prohibited by, for instance, Article 13.

[16] Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Convention on Human Rights and Biomedicine) (adopted 4 April 1997, entered into force 1 February 1999) CETS 164.

[17] H Devlin, 'Britain's House of Lords Approves Conception of Three-Person Babies', *The Guardian*, 24 February 2015 <http://www.theguardian.com/politics/2015/feb/24/uk-house-of-lords-approves-conception-of-three-person-babies> accessed 20 March 2015.

[18] ibid. Also see, eg, ethicist John Harris's viewpoint as voiced in S Connor, 'Scientist Who Pioneered "Three-Parent" IVF Embryo Technique Now Wants to Offer It to Older Women Trying for a Baby', *The Independent*, 8 February 2015 <http://www.independent.co.uk/news/science/threeparent-embryos-an-ivf-revolution-or-a-slippery-slope-to-designer-babies-10031477.html> accessed 14 May 2015.

[19] A Regalado, 'Engineering the Perfect Baby', *MIT Technology Review*, 5 March 2015 <http://www.technologyreview.com/featuredstory/535661/engineering-the-perfect-baby/> accessed 10 May 2015; and E Lanphier, F Urnov, S Ehlen Haecker et al, 'Don't Edit the Human Germline' (2015) 519 *Nature* 410; D Baltimore, P Berg, M Botchan et al, 'A Prudent Path Forward for Genomic Engineering and Germline Gene Modification', (2015) 348 (6230) *Science* 36.

[20] Baltimore et al, ibid, 38.

[21] Regalado, 'Engineering the Perfect Baby' (n 19).

The question is how this legal ban will affect current scientific developments, and, vice versa, how these technologies will affect the legal status of Article 13. The aforementioned articles suggest that for now, a majority within the scientific community is in favour of a moratorium on human gene-editing. However, this could change since, as will be discussed below, many of the current objections are not absolute in nature. In addition, one can doubt how effective legal bans on human genetic engineering will prove to be. International legal documents, such as the Convention on Human Rights and Biomedicine, have not been ratified in many countries. Moreover, even if they have been, the question is how they can be enforced. Indeed, shortly after the international discussion on a possible moratorium had begun, a group of Chinese scientists announced that they had already applied CRISPR-Cas9 to human embryos to modify an aberrant gene that causes beta-thalassaemia, albeit with mixed results.[22] Finally, because the legal ban on human genetic engineering is one of the central provisions in international biolaw, the rise of human genetic modification raises the larger question of what the projected risks are against which biolaw aims to protect, and why the biolegal framework features quite a pessimistic outlook on the possible outcomes of biomedical developments. Section 7.2.2 focuses on these last questions.

7.2.2 Biolaw's dystopian approaches to utopian technologies

Biomedical technologies enable interventions with the human body and human life on a biogenetic level. From the perspective of the biosciences, human life is perceived as a set of building blocks which can be regrouped, remodelled, rebuilt, recombined, and replicated at will. As such, biomedical interventions may have far-reaching effects on a collective level, both positive and negative. Indeed, according to the human rights conventions and declarations that have been developed since the 1990s to regulate biomedical developments, these technologies ultimately affect the interests of humanity, both in the present and the future. The preamble of the Convention on Human Rights and Biomedicine (Council of Europe) describes these interests as follows:

> Conscious that the misuse of biology and medicine may lead to acts endangering human dignity;
>
> Affirming that progress in biology and medicine should be used for the benefit of present and future generations;
>
> Stressing the need for international co-operation so that all humanity may enjoy the benefits of biology and medicine.

Even if these sentences also stress the huge possible benefits of biomedical science, in general, international biolaw seems to focus more on its potential harms and dangers. It could be said, somewhat paradoxically, that within the legal regulation of these 'utopian

[22] I Sample, 'Scientists Genetically Modify Human Embryos in Controversial World First', *The Guardian*, 23 April 2015 <http://www.theguardian.com/science/2015/apr/23/scientists-genetically-modify-human-embryos-in-controversial-world-first> accessed 10 May 2015.

technologies', dystopian scenarios tend to prevail. Accordingly, the legal framework of biomedical regulation is characterized by prohibitions on and restrictions of the use and development of biomedical technologies. The most important international conventions and declarations in this field prohibit, in addition to human germline genetic modification, eugenic practices, in particular those aiming at the selection of persons,[23] using ARTs to select a future child's sex,[24] the creation of human embryos for research purposes,[25] the use of the human body and its parts for financial gain,[26] and creating genetically identical human beings.[27]

All these prohibitions involve speculation on several levels. As some of these technologies, such as human cloning, have not been developed yet, and as the actual effects of these technologies are therefore as yet unknown, these prohibitions necessarily involve the regulation of potential, future situations. Moreover, these provisions aim to protect the interests of possible future legal subjects. Some technologies, such as ARTs, look to the creation of future persons; others establish genetic changes which can be passed down to future generations. Finally, to express the possible harms involved, relatively vague expressions are used, such as respect for human life and human dignity. In all these cases it remains unclear what the views of these future people on these technologies will be, or how their fates will be exactly affected. Techno-optimists view these uncertainties as a major weakness of current international regulation of biomedical developments. At the aforementioned global summit, BEINGS 2015, for instance, a recurring complaint was that vague fears and highly speculative harms are now thwarting biomedical progress, thereby standing in the way of saving millions of lives. Moreover, the cautious and even dystopian tenet within ethical and legal approaches to biomedical technologies was heavily criticized. As one of the summit's participants voiced his disdain: 'we need to resist bowing at the altar of amorphous existential risks without identifiable harms'.[28]

These criticisms have been largely left unanswered in legal discourse. One of the central arguments in this chapter is that the anti-utopian approach advocated by Jonas in *The Imperative of Responsibility* can fill this gap. His view of emerging technologies and their accompanying uncertainties can explain the cautious approach to biomedical technologies that is generally employed in international law.

[23] EU Charter of Fundamental Rights (adopted 18 December 2000, entered into force 1 December 2009), OJEC C 364, art 3(2)(b).

[24] Convention on Human Rights and Biomedicine, art 14.

[25] Convention on Human Rights and Biomedicine, art 18(2).

[26] Convention on Human Rights and Biomedicine, art 21; EU Charter of Fundamental Rights (n 23), art 3(2)(c).

[27] Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings (adopted 12 January 1998, entered into force 1 March 2001) CETS No 168, art 1; EU Charter of Fundamental Rights (n 23), art 3(2)(d); Universal Declaration on the Human Genome and Human Rights (adopted 11 November 1997, the United Nations Educational, Scientific and Cultural Organization (UNESCO) Res 29 C/17, endorsed by UN General Assembly Declaration, United Nations General Assembly (UNGA) Res 53/152, 9 December 1998), art 11.

[28] M Darnovsky, 'Tired Tropes and New Twists in the Debate about Human Germline Modification', *Biopolitical Times*, 28 May 2015 <http://www.biopoliticaltimes.org/article.php?id=8618> accessed 3 December 2015.

According to Jonas, emerging technologies are of such an unprecedented, utopian scale, and will have such far-reaching effects for the future of mankind, that they necessitate a new ethical paradigm. The new type of ethics which he advocates does not limit itself to establishing the rights and duties towards contemporary members of the legal community, but also takes into account responsibilities towards future generations. Within his *Fernethik*, 'the indefinite future, rather than the contemporary context of the action, constitutes the relevant horizon of responsibility'.[29] As a starting point to this future-oriented type of ethics, Jonas formulates his famous revision of Kant's categorical imperative to express the responsibilities to future people: 'Act so that the effects of your action are compatible with the permanence of genuine human life.'[30]

Nevertheless, it is clear that predictions of the long-range effects of our technological actions are characterized by a high level of uncertainty. Jonas describes our current predicament as follows:

> Living now constantly in the shadow of unwanted, built-in, automatic utopianism, we are constantly confronted with issues whose positive choice requires supreme wisdom—an impossible situation for man in general, because he does not possess that wisdom, and in particular for contemporary man, because he denies the very existence of its object, namely, objective value and truth. We need wisdom most when we believe in it least.[31]

As a result, a certain degree of imagination and speculation is inevitable in legal and ethical frameworks that are developed to regulate technological interventions. For Jonas, this state of affairs does not pose an insurmountable obstacle. On the contrary, it forms the starting point for his ethic of the future. In this vein, as will be discussed in a later section, Jonas uses imagination as the cornerstone of his methodological approach. Moreover, for him uncertainty has important normative implications, which he expresses through the formulation of a new ethical principle. This principle commands ethical and legal decision-making 'to give in matters of a certain magnitude—those with apocalyptic potential—greater weight to the prognosis of doom than to that of bliss'.[32] For his proposed precautionary and overtly anti-utopian approach, Jonas offers three reasons.[33] First, by taking evolution in our own hands, we are compressing the slow and gradual process of natural evolution, with its small 'mistakes' along the way, into a much more fast-paced and ambitious process of reform of human nature, with accordingly much larger, even catastrophic risks. As a result, the stakes involved in technological interferences with human evolution will be much higher and its potential effects more radical than is the case with natural evolution. Second, Jonas observes that technological developments often gather an internal dynamic and momentum of their own, escaping from explicit moral deliberation. Third, he argues that precaution is in place because ultimately nothing less than human nature is at stake.

[29] Jonas, *The Imperative of Responsibility* (n 6) 9. [30] ibid, 11. [31] ibid, 21.
[32] ibid, 34. [33] ibid, 31–33.

7.3 Imagining the Dangers of Human Genetic Modification within Biolaw

Jonas's anti-utopian approach is able to explain the dominance of dystopian scenarios within biolaw. Moreover, his proposal to give priority to negative prognoses over positive ones corresponds with the precautionary approaches which can be recognized within international biolaw. However, an important question remains unanswered: what is the exact nature of the risks involved in regulation of contested biomedical developments?

In order to answer this question, this section focuses on the rationale behind the ban on altering the human germline, as expressed in Article 13. Three possible scenarios that may have influenced Article 13 will be sketched and explored: the scenarios of classic risk governance, existential risk, and dangers to human dignity. Which reading offers the most convincing explanation of the ban on human genetic germline modification in light of the Explanatory Report to the Convention?[34] Answering this question will allow, more generally, a better understanding of the special nature of risk within biolegal discourse.

A first possible reading of the ban is that the application of this technology to the human genome is still unsafe and poses serious health risks for those involved. As the scientists who are calling for a moratorium point out, 'the precise effects of genetic modification to an embryo may be impossible to know until after birth' and 'potential problems may not surface for years'.[35] Their main recommendations are more research and better education of the public by experts 'about this new era of human biology'.[36]

The clinical risks of the technology of human gene-editing, in its current stage of development, certainly warrant a classic system of risk governance based on the precautionary approach. After all, although the precautionary principle is most famously applied in the field of environmental law, it is also widely accepted to apply to public health interests.[37] Additionally, some of the concerns about interventions with the human genome resemble concerns which can be recognized in environmental law. To a certain extent, genetically modified organisms (GMOs), for instance, raise concerns similar to those raised by genetically modified human embryos. Similarly, protection of biodiversity could be understood to include protection of diversity in the human gene pool.

However, it seems that a traditional risk approach falls short within public deliberation on this issue on several levels. A risk approach seems to turn the issue

[34] *Explanatory Report to the Convention on Human Rights and Biomedicine*, DIR/JUR (97)5 <http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164> accessed 18 February 2017.

[35] Lanphier et al, 'Don't Edit the Human Germline' (n 19) 411.

[36] Baltimore et al, 'A Prudent Path' (n 19) 38.

[37] As the European Commission notes in its communication on the principle, 'The precautionary principle is not defined in the Treaty, which prescribes it only once—to protect the environment. But in practice, its scope is much wider, and specifically where preliminary objective scientific evaluation indicates that there are reasonable grounds for concern that the potentially dangerous effects on the environment, human, animal or plant health may be inconsistent with the high level of protection

of human gene-editing into merely a safety issue. From that perspective, all that is needed is a scientific assessment of the clinical risks involved in human gene-editing. These should then be weighed against the possible clinical benefits. The public debate would then merely have to focus on finding a balance between these scientific perspectives. However, such an approach ignores key aspects of the issue of human gene modification. As a group of scholars, including prominent science and technologies scholar Sheila Jasanoff, eloquently describes the deficit of a classic risk approach to human genome engineering as a reaction to the aforementioned call for a moratorium on human gene-editing:

> the problem is not simply a lack of technical knowledge. The answer to how we should act does not lie in the technological details of CRISPR. It is our responsibility to decide, as parents and citizens, whether our current genetic preferences should be edited, for all time, into our children and our children's children. A moratorium without provisions for ongoing public deliberation narrows our understanding of risks and bypasses democracy…. Even in technologically advanced societies, we tend to defer to expert judgments about which risks are reasonable to worry about, and which are not. This is a democratic deficit. *It inhibits our capacity to participate thoughtfully in imagining the futures we want and governing technological change accordingly* [emphasis added].[38]

In other words, a classic risk approach to human gene-editing obfuscates the essentially political and moral nature of this issue. Indeed, even if gene-editing would be safe for clinical application in humans, this still would not take away many of the most serious concerns that people have about this technology. In fact, the comments in the Explanatory Report to the Convention of Human Rights and Biomedicine on Article 13 hardly mention patient safety. The concerns seem of a larger scale than can be grasped from a clinical risk perspective. As the Explanatory Report states:

> The progress of science, in particular in knowledge of the human genome and its application, has raised very positive perspectives, but also questions and even great fears. Whilst developments in this field may lead to great benefit for humanity, misuse of these developments may endanger not only the individual but the species itself.[39]

In other words, human germline genetic engineering not only poses risks to public health, but also to the continued existence of the entire human species. Similarly, within biolegal scholarly literature, concerns about the future of the human species have been expressed within the context of human genetic engineering. For instance, health law scholar George Annas warns that lifting the ban on this technology may open the door to genetic genocide.[40] By this he means that 'inheritable

chosen for the Community', Commission of the European Communities, 'Communication on the Precautionary Principle', *COM* (2000)1 (2 February 2000) 3.

[38] S Jasanoff, JB Hurlbut, and K Saha, 'Human Genetic Engineering Demands More Than a Moratorium', *The Guardian* (7 April 2015) <http://www.theguardian.com/science/political-science/2015/apr/07/human-genetic-engineering-demands-more-than-a-moratorium> accessed 11 May 2015.

[39] *Explanatory Report to the Convention on Human Rights and Biomedicine* (n 34) para 89.

[40] See, eg, G Annas, 'Crimes Against the Human Species (Type II Crimes Against Humanity Explained)' in BC van Beers et al (eds), *Humanity Across International Law and Biolaw* (CUP 2015) 129.

genetic alteration carries the prospect of developing a new species of humans that could turn into either destroyers or victims of the human species'.[41] Additionally, in order to protect 'the endangered human', Annas, together with scholars Isasi and Andrews, proposes a *Convention on the Preservation of the Species*. As they write, their project can be described as conservative in that they seek to conserve the human species.[42] Their 'bioconservatism', as the school of thought which unites all sorts of different criticisms of biomedical technologies is called,[43] can therefore be understood quite literally as aimed at biogenetic conservation. Their concerns seem to echo Hawking's aforementioned fear that new forms of artificial intelligence might spell the end of the human race.

The type of risk that surfaces in both Hawking's and Annas's thoughts could be described as existential risk. Nick Bostrom, prominent transhumanist scholar and director of the Oxford Future of Humanity Institute, offers the following definition: 'an existential risk is one that threatens the premature extinction of Earth-originating intelligent life or the permanent and drastic destruction of its potential for desirable future development'.[44] More than a traditional risk perspective, this approach is able to grasp the large scale of the stakes involved in human genetic engineering. As the preambles to the most important conventions and declarations in this legal field emphasize, it is indeed ultimately mankind, the human species, humanity or however one wishes to designate the human collective, that is involved in the biomedical project. Similarly, Habermas describes the ethics that should guide us within the regulation of human genetic engineering as an 'ethics of the species' (*Gattungsethik*).[45]

Nevertheless, even if texts of international biolaw seem to originate in a fear that our humanity is at risk, the existential risk approach is not able to get to the core of the ban on human germline modifications. The main problem is that an existential risk approach seems to reduce the ban on human germline modification to a special measure of wildlife conservation, with the difference being that it is now humans who are protected as endangered species. Yet, a closer look at Article 13 reveals that it is not the fear of human extinction, decimation, or other grave material risks for the human species which serves as guiding thought, but rather a fear of the destruction of humanity in less tangible ways. As is written in the subsequent words of the Explanatory Report to Article 13: 'The ultimate fear is of intentional modification of the human genome so as to produce individuals or entire groups endowed with particular characteristics and required qualities.'[46] In other words, regardless of the safety issues involved in germline modification, and

[41] GJ Annas, LB Andrews, and RM Isasi, 'Protecting the Endangered Human: Toward an International Treaty Prohibiting Cloning and Inheritable Alterations' (2002) 28 *American Journal of Law & Medicine* 151.

[42] ibid.

[43] In debates on biomedical issues, it is common to distinguish bioconservatives from transhumanists. See, eg, N Bostrom, 'In Defense of Posthuman Dignity' (2005) 19 *Bioethics* 202.

[44] N Bostrom, 'Existential Risk Prevention as Global Priority' (2013) 4(1) *Global Policy* 15.

[45] Habermas, *The Future of Human Nature* (n 12) 71.

[46] *Explanatory Report to the Convention on Human Rights and Biomedicine* (n 34) para 89.

the question whether this technology would put the prolonged existence of the human species at risk, it is undesirable to produce human individuals or groups according to a certain design or to satisfy a list of desired characteristics. Even if the remaining comments on Article 13 do not offer further explanation of these vague words, it is clear that, according to this Article, the main problem resides in the fact that human genetic modification opens up the possibility of one person designing the other.

It is perhaps not a coincidence that the Explanatory Report does not offer more guidance. The harm involved in the resulting 'self-instrumentalisation of the species'[47] is hard to put into words. It goes beyond the harm principle, and beyond a violation of rights. As French biolegal scholar Labrusse-Riou states: 'The problem is that nobody suffers in this issue. What suffers is society, the frame of reference, culture, which is probably graver.'[48] Indeed, as many philosophers writing on these issues point out, whether they are in favour of the use of these technologies or not, the prospect of one person designing the other calls into question no less than the foundational distinctions of any rights-based system of governance:[49] the distinction between persons and things,[50] between chance and choice,[51] and between the given and the made.[52] In legal philosopher Ronald Dworkin's words:

> The overall structure of our moral and ethical experience … depends, crucially on a fundamental distinction between what we are responsible for doing or deciding, individually or collectively, and what is given to us, as a background against which we act or decide, but which we are powerless to change…. We dread the prospect of people designing other people because that possibility in itself shifts … the chance/choice boundary that structures our values as a whole, and such a shift threatens, not to offend any of our present values, derivative or detached, but, on the contrary, to make a great part of these suddenly obsolete.[53]

[47] Habermas, *The Future of Human Nature* (n 12) 66.

[48] Labrusse-Riou made these remarks as a member of the French national ethical committee CCNE. See M Marcuzzi, 'La revendication des corps' in E Dockès and G Lhuilier (eds), *Le corps et ses représentations* (Litec 2001) 31.

[49] In Fukuyama's words, 'What is it that we want to protect from any future advances in biotechnology? The answer is, we want to protect the full range of our complex, evolved natures against attempts at self-modification. We do not want to disrupt either the unity or the continuity of human nature, and thereby the human rights that are based on it.' F Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (Farrar, Straus en Giroux 2002) 172.

[50] In Habermas's words: '[…] advances of genetic engineering tend to blur the deeply rooted categorical distinctions between the subjective and the objective, the grown and the made. What is at stake, therefore, with the instrumentalization of prepersonal life is the ethical self-understanding of the species, which is crucial for whether or not we may go on to see ourselves as committed to moral judgment and action.' Habermas, *The Future of Human Nature* (n 12) 71.

[51] R Dworkin, 'Playing God: Genes, Clones, and Luck' in R Dworkin, *Sovereign Virtue. The Theory and Practice of Equality* (Harvard University Press 2000) 443–44.

[52] In Sandel's words, 'To appreciate children as gifts is to accept them as they come, not as objects of our design, or products of our will, or instruments of our ambition.' M Sandel, *The Case Against Perfection: Ethics in the Age of Genetic Engineering* (Harvard University Press 2007) 45.

[53] Dworkin 'Playing God' (n 51) 443–44.

Correspondingly, the feared harm does not seem to be of a physical nature, as in public health concerns or fears for 'genetic genocide'. Instead, what is feared could be described as a 'metaphysical destruction', in the words of international law scholar Delmas-Marty.[54] As Jonas also points out, such metaphysical or symbolic 'risks' do not lend themselves to risk calculation, as they can hardly be measured and weighed.[55]

In a similar vein, if human genetic modification is believed to touch upon human nature, it is not so much human nature in the biological or genetic sense of the word. In a way, it makes no sense to want to conserve the human genome as it is. As Article 3 of UNESCO'S Universal Declaration on the Human Genome and Human Rights[56] aptly states: 'The human genome, which by its nature evolves, is subject to mutations.' Rather, the reason why humanity may be affected by human genetic engineering is that it seems to undermine our 'normative self-understanding', in Habermas's words.[57] By this he means the image of the person on which legal and ethical systems of thought are based: the view of the person as an end in himself, endowed with an intrinsic and absolute value, who is to be distinguished from things, animals, instruments, and commodities.

The common expression for this normative view of humanity, also in legal discourse, is, of course, human dignity. Until recently, one could regard human dignity's normative view of mankind as 'merely' the founding fiction of human rights discourse, and therefore consider its meaning hardly legally relevant outside the context of the preambles to international human rights declarations and conventions. However, within the context of international biolaw, human dignity's image of humanity has been reinvented as a legal guideline for the technological remaking of human nature. It has become part of a normative anthropology that has been developed to guide the technological remaking of the human species.

As such, human dignity has been elevated to being the central principle within legal regulation of biomedical developments, both on a national and an international level. As the Explanatory Report to the Convention on Human Rights and Biomedicine states, 'The concept of human dignity, which is also highlighted, constitutes the essential value to be upheld. It is at the basis of most of the values emphasised in the Convention.'[58] Nevertheless, the meaning of human dignity remains shrouded in controversy, also on a legal level. One of the main problems is that the normative image of humanity, as implied by human dignity, is surrounded by fictions and speculations which are not grounded in empirical reality, let alone biogenetic reality.

[54] M Delmas-Marty, 'Certitude et Incertitudes du Droit' in H Atlan et al (eds), *Le Clonage Humain* (Le Seuil 1999) 92.

[55] Jonas, *The Imperative of Responsibility* (n 6) 33–34.

[56] Universal Declaration on the Human Genome and Human Rights (n 27).

[57] Habermas, *The Future of Human Nature* (n 12) 72.

[58] *Explanatory Report to the Convention of Human Rights and Biomedicine* (n 34) para 9.

7.4 From Science Fiction to the Legal Fiction of Human Dignity

As discussed in section 7.3, the uncertainties involved in biomedical technologies necessitate a legal approach which exceeds the level of protection offered by traditional modes of risk governance. It could be said that through this special legal approach, a new level of speculation is introduced. Biomedical regulation does not only rely on 'what-if' scenarios and prognoses of possible effects, but also operationalizes a fictional, normative account of mankind: the subject of human dignity. As Article 1 of the Universal Declaration of Human Rights[59] describes that subject, 'All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.' Interestingly, the dystopian scenarios of biolaw are thus mobilized to protect a rather utopian view of man.

The idealized and at the same time inherently contradictory nature of that view of mankind is not a secret. In fact, it is clear, as the Declaration's preamble also states, that this image of humanity was invoked in post-war human rights discourse as a reaction to the historical fact that 'disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind'. Nevertheless, the fictional character of human rights and their implicit view of man is attacked every now and again, whether it is by calling human rights discourse 'nonsense upon stilts'[60] or by comparing the belief in human rights with the belief in witches and unicorns.[61]

Since the rebirth of human dignity within the context of international biolaw, the critique of the fictional character seems to have revived. From that perspective, within the context of biolaw, Schmitt's notorious adage 'whoever says humanity, seeks to deceive' has gained new significance. More generally, the biosciences seem to have caused new tensions between normative and empirical views of the human. On the one hand, in response to biomedical developments, legal scholars reaffirm their belief in human rights as 'a revolt against the laws of nature, a refusal to stay confined within the limits of the biological conception of man'.[62] On the other hand, from the perspective of the biosciences, the belief in *liberté, égalité, fraternité*, which could be regarded as an important founding 'myth' of human rights, seems to lose much of its credibility.

This latter tenet becomes clear upon closer inspection of the motto's three components in the light of biomedical developments. All human beings are born free

[59] Adopted 10 December 1948, UN General Assembly Resolution 217A(III), GAOR, 3rd Sess, Part I, Resns, 71.

[60] J Bentham, *Anarchical Fallacies; Being an Examination of the Declaration of Rights Issued During the French Revolution* (1792), line 198 <http://oll.libertyfund.org/titles/bentham-the-works-of-jeremy-bentham-vol-2/simple#lf0872-02_label_001> accessed 17 May 2015.

[61] A MacIntyre, *After Virtue: A Study in Moral Theory* (Gerald Duckworth 1981) 67.

[62] Delmas-Marty, 'Certitude et Incertitudes' (n 54) 107 (author's translation).

in human rights discourse, yet in biological reality many chances in life appear to depend on genetic predispositions. All human beings are born equal, yet knowledge of our genomes is bringing new inequalities to light. Finally, when it comes to brotherhood, the question is to what extent current systems of solidarity will be undermined now that the life sciences are lifting the 'veil of ignorance' which covered our genetic fates until recently. Human genome-editing will cause even more friction between biomedical and dignity-based views of humanity. In this vein, UNESCO's International Bioethics Committee expresses the following fear in a statement on human genome-editing:

> The goal of enhancing individuals and the human species by engineering the genes related to some characteristics and traits … impinges upon the principle of respect for human dignity in several ways. It weakens the idea that the differences among human beings, regardless of the measure of their endowment, are exactly what the recognition of their equality presupposes and therefore protects. It introduces the risk of new forms of discrimination and stigmatization for those who cannot afford such enhancement or simply do not want to resort to it.[63]

Consequently, an increasingly popular line of attack on human dignity is to depict it as a harmful fiction, not grounded in reality. A recent piece, tellingly entitled 'The Stupidity of Dignity', written by well-known Harvard psychologist Steven Pinker, can serve as an example of this tendency to debunk the fiction of human dignity on empirical grounds. According to Pinker, the concept of human dignity has gained too much importance in public debates on biomedical issues. In his view, dignity is nothing more than a phenomenon of human perception: '[j]ust as the smell of baking bread triggers a desire to eat it, and the sight of a baby's face triggers a desire to protect it, the appearance of dignity triggers a desire to esteem and respect the dignified person'.[64] Pinker contrasts his view of dignity with the prevailing interpretation of human dignity underpinning biomedical laws. One of his prime allegations is that such readings of human dignity are out of touch with reality:

> Ever since the cloning of Dolly the sheep a decade ago, the panic sown by conservative bioethicists, amplified by a sensationalist press, has turned the public discussion of bioethics into a miasma of scientific illiteracy. *Brave New World*, a work of fiction, is treated as inerrant prophesy. Cloning is confused with resurrecting the dead or mass-producing babies. Longevity becomes 'immortality', improvement becomes 'perfection', the screening for disease genes becomes 'designer babies' or even 'reshaping the species'. The reality is that biomedical research is a Sisyphean struggle to eke small increments in health from a staggeringly complex, entropy-beset human body…. In every age, prophets foresee dystopias that never materialize, while failing to anticipate the real revolutions.[65]

[63] UNESCO International Bioethics Committee, *Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights* (Paris 2015) <http://unesdoc.unesco.org/images/0023/002332/233258E.pdf> accessed 3 December 2015.

[64] S Pinker, 'The Stupidity of Dignity: Conservative Bioethics' Latest, Most Dangerous Ploy', *The New Republic*, 28 May 2008 <https://newrepublic.com/article/64674/the-stupidity-dignity> accessed 14 May 2015.

[65] ibid.

In other words, Pinker reduces the humanizing legal fiction of human dignity to the type of fiction involved in science fiction. According to him, only evidence-based arguments, which demonstrate clear and identifiable harms of certain technologies, can serve as a reason to restrict biomedical research. Any other considerations, such as the question what kind of future we want for the human species, seems of no importance. This raises the question of what Pinker's view is on ethics. In an opinion on CRISPR, Pinker offers a clear answer to this question:

> The primary moral goal for today's bioethics can be summarized in a single sentence. *Get out of the way.* A truly ethical bioethics should not bog down research in red tape, moratoria, or threats of prosecution based on nebulous but sweeping principles such as 'dignity,' 'sacredness,' or 'social justice'. Nor should it thwart research that has likely benefits now or in the near future by sowing panic about speculative harms in the distant future.[66]

Although Pinker's approach is based on a rather caricatured and reductionist view of human dignity, his polemic against the role of human dignity in bioethics and biolaw does raise a valid question: how can the reliance on imagination and doom scenarios within the context of biolaw be justified? Indeed, biolegal discourse seems to be replete with fictions, speculations, and allusions to dystopian scenarios of the future. Moreover, there does seem to be a special connection between human dignity and imagination, even if most people will agree, unlike Pinker, that human dignity is more than mere science fiction. The question then becomes what the role of imagination and the fiction of human dignity should be in coming to a legal understanding of the possible dangers involved in biomedical developments.

To come to a better understanding of the role of imagination within regulation of emerging technologies in general, and the role of human dignity's *homme rêvé*[67] more specifically, Jonas's reflection offers several clues. To unfold the role of imagination for the development of moral and legal frameworks to guide emerging technologies, Jonas uses the concept of 'the heuristics of fear'. According to the heuristics of fear, 'moral philosophy must consult our fears prior to our wishes to learn what we really cherish'.[68] In other words, an imagination of the risks and dangers of future developments is heuristically needed to uncover, identify, and explicate the principles at stake. Ultimately, this negative approach can, in Jonas's view, also lead to a better understanding of the meaning of human dignity in these issues. In Jonas's words:

> Just as we should not know about the sanctity of life if we did not know about killing …; and just as we should not know the value of truth without being aware of lies, nor of freedom without the lack of it, and so forth—so also in our search after an ethics of responsibility for distant contingencies, it is an anticipated *distortion* of man that helps us to detect that in the

[66] S Pinker, 'The Moral Imperative for Bioethics', *The Boston Globe*, 1 August 2015 <https://www.bostonglobe.com/opinion/2015/07/31/the-moral-imperative-for-bioethics/JmEkoyzlTAu9oQV76JrK9N/story.html> accessed 2 December 2015.

[67] Delmas-Marty, 'Certitude et Incertitudes' (n 54) 107; DWJM Pessers, *Menselijke Waardigheid en het Persoonsbegrip in het Recht* (Lemma 2005).

[68] Jonas, *The Imperative of Responsibility* (n 6) 27.

normative conception of man which is to be preserved from it. And we need the *threat* to the image of man—and rather specific kinds of threat—to assure ourselves of his true image by the very recoil from these threats.[69]

Jonas's reliance on negative scenarios, which also surfaces in this quote, has already been discussed in the previous sections. What seems more interesting, at this point, is which new role for law and morality is implied by his heuristics of fear. In general, two different interpretations are possible.

A first interpretation of Jonas's heuristics of fear emphasizes the aspect of fear as a guideline for decision-making. Within this line of thinking, there is a truth to the primitive feelings and basic intuitions raised by biomedical developments. Indeed, Jonas himself writes that 'the revulsion of feeling which acts ahead of knowledge'[70] can help us apprehend the values at stake.

In a similar vein, a certain strand in bioethical thought stresses the wisdom hiding in feelings of repugnance. Probably the best known effort to bring this line of thought to fruition comes from Leon Kass, one of the central targets of Pinker's rant against theoconservative ('theocon') bioethics. Kass himself explains the wisdom of repugnance in an article with the same title:

> Revulsion is not an argument; and some of yesterday's repugnances are today calmly accepted—though, one must add, not always for the better. In crucial cases, however, repugnance is the emotional expression of deep wisdom, beyond reason's power fully to articulate it.[71]

A more moderate version of Kass's wisdom of repugnance can be recognized in Michael Sandel's essay *The Case Against Perfection*. Although the feelings of 'moral vertigo' and 'unease' which are raised by biomedical developments can hardly be expressed in terms of conventional arguments such as autonomy, fairness, and individual rights, this fact is, according to Sandel, only a sign that contemporary 'science is moving faster than moral understanding'.[72] Similarly, Habermas argues that the 'revulsion' many of us feel at being confronted with 'the chimaera that bear witness to a violation of the species boundaries that we had naively assumed to be inalterable', or the 'disgust' we experience when thinking about the creation of embryos for industrial purposes, is an indication of the fact that biomedical technologies ultimately 'affect the very concept we have of ourselves as cultural members of the species of "humanity" '.[73]

Kass's proposal to use feelings of revulsion and repugnance as signposts for normative deliberation has been heavily criticized.[74] Indeed, to rely on unreflected intuitions, gut feelings, and primitive emotions within the regulation of these issues brings with it a major risk of unfounded, prejudiced, and irrational conservatism.

[69] ibid, 26–27. [70] ibid, 27.
[71] LR Kass, 'The Wisdom of Repugnance', (1997) 216(22) *New Republic* (2 June 1997) 17–26, 22.
[72] Sandel, *The Case Against Perfection* (n 52) 9.
[73] Habermas, *The Future of Human Nature* (n 12) 39–40.
[74] See, eg, J Harris, 'Clones, Genes and Human Rights' in J Burley (ed), *The Genetic Revolution and Human Rights. The Oxford Amnesty Lectures 1998* (OUP 1999) 82–83; MC Nussbaum, *Hiding from Humanity. Disgust, Shame, and the Law* (Princeton University Press 2004) 81–82.

Correspondingly, human dignity within this approach quickly devaluates into either a 'theocon' slogan used to cover up the absence of sound arguments, as Pinker writes, or into a knock-down argument against which no counter-evidence is possible.

Nevertheless, the less radical approach of Sandel and Habermas to the role of intuitions and emotions in bioethical decision-making still leaves the door open to a second, more constructive interpretation of Jonas's heuristics of fear. Within this interpretation, the important role of imagination and symbolization for legal and ethical decision-making on biomedical developments is emphasized. According to this reading of Jonas's heuristics of fear, lawyers and ethicists must first visualize and imagine the possible long-range effects of anticipated technological developments, to be able to develop a proper normative framework. As Jonas describes this new type of anticipatory ethical and legal reflection:

> What is here contemplated, therefore, is a casuistry of the imagination which, unlike the customary casuistries of law and morality that serve the trying out of principles already known assists in the tracking and discovering of principles still unknown. The serious side of science fiction lies precisely in its performing such well-informed thought experiments, whose vivid imaginary results may assume the heuristic function here proposed. (See, eg, A Huxley's *Brave New World*).[75]

Whereas Pinker refers to omnipresent allusions to *Brave New World* as an example of the naïve and unrealistic worldview of many contemporary biolawyers and bioethicists, Jonas regards the use of imagination in legal-ethical contexts and the reliance on dystopian scenarios as indispensable for the development of new normative frameworks. In a way, it is only logical that as a reaction to the utopian scale of current technological developments, and the techno-theological beliefs and aspirations of the scientists involved, a legal discourse has come into being which equally relies on imaginations and fictions. From that perspective, biolaw's dystopian scenarios on the possible dangers of emerging technologies counterbalance the utopian scenarios in which emerging technologies ultimately root.

Moreover, in answer to Pinker's critique, it can be stressed that Jonas's 'casuistry of the imagination' is intended to be mobilized at a preliminary stage of decision-making; that is, during the construction of a normative framework for further deliberation. It only serves as a heuristic device to detect the principles and interests worth protecting. This means that when it comes to application of these newly found principles to specific situations, mere imagination cannot suffice. As Jonas puts it, in that stage of decision-making, the uncertainty of 'long-term projections becomes a grievous weakness'.[76] Instead, from then on, more realistic prognoses of the future need to take over. Nevertheless, the basic uncertainty of future consequences remains. At this point in his line of reasoning, Jonas unfolds his precautionary rule that in political deliberation on technological developments the bad prognosis should prevail over the good one.

[75] Jonas, *The Imperative of Responsibility* (n 6) 30.
[76] ibid.

Jonas's case for the use of imagination in legal and ethical approaches to technological developments is able to offer new perspectives on the role of biolaw and its central principle—human dignity—in the regulation of biomedical developments.[77] First, his approach throws light on the deficit of traditional concepts of risk, as exemplified by risk assessment discourse. It could be said that scientists such as Pinker, who argue for 'evidence-based' regulation, in which solely tangible risks offer enough weight for legal bans and restrictions, make use of a very 'narrow imagination of risk'.[78] Such a narrow conception of risk, often accompanied by a certain disdain for notions such as human dignity, seems to go back to what could be called a scientistic tendency within debates on emerging technologies; the thought that it should be ultimately up to scientists to decide what counts as risk, and thus as a sufficient ground for more restrictive approaches. The scientistic bias can lead to a conceptual impoverishment of democratic deliberation, disengaging the public from moral and political reflection on the question of which goals emerging technologies should serve. As Hurlbutt writes in an article on the governance of human genome-editing: '[i]t is our technologies that should be subject to democratically articulated imaginations of the future we want, not the opposite…. Imagining what is right and appropriate for our world—and what threatens its moral foundations—is a task for democracy, not for science.'[79] The importance of the principle of human dignity for public, democratic deliberation on this issue can be explained against this background. The legal concept of human dignity can be regarded as an essential tool for citizens in democratic societies to imagine the future that they want for humanity, and to use that moral imagination as a guideline for biomedical regulation.

Moreover, contrary to what Pinker seems to believe, the use of imagination in bioethical and biolegal deliberation can also be used in more nuanced ways than merely posing blanket legal bans. For example, more implicit images of the human can be discerned within legal frameworks which offer practical rules for the creation, transfer, and conservation of technological hybrids of human origin in contemporary bioeconomies, such as human immortalized cell lines, human embryonic stem cells, or frozen human egg cells. Within legal discourse, these human semi-objects are not treated as normal objects of property law that can be sold or used for industrial purposes, but instead symbolized as objects with a special status.[80]

[77] In this chapter, I focus on the importance of imagination for biolegal decision-making. For reflection on the importance of imagination for ethical decision-making on emerging technologies, see M Coeckelberg, *Human Being @ Risk: Enhancement, Technology and the Evaluation of Vulnerability Transformations* (Springer 2013) 103–06.

[78] S Jasanoff, JB Hurlbutt, and K Saha, 'CRISPR Democracy: Gene Editing and the Need for Inclusive Deliberation' (2015) 32 *Issues in Science and Technology* <http://issues.org/32-1/crispr-democracy-gene-editing-and-the-need-for-inclusive-deliberation/> accessed 2 December 2015.

[79] JB Hurlbutt, 'Limits of Responsibility: Genome Editing, Asilomar, and the Politics of Deliberation' (2015) 5 *Hastings Center Report* 12.

[80] See, eg, D Dickenson, *Property in the Body: Feminist Perspectives* (CUP 2007); M Quigley, 'Property in Human Biomaterials—Separating Persons and Things?' (2012) 32 *Oxford Journal of Legal Studies* 659; J Wall, 'The Legal Status of Body Parts: A Framework' (2011) 31 *Oxford Journal of Legal Studies* 783; R Rao, 'Genes and Spleens: Property, Contract, or Privacy Rights in the Human Body?' (2007) 35 *J L Med Ethics* 371.

Additionally, Jonas's appeal to legal and ethical imagination finds resonance with the fact that also, on a deeper level, 'law is part of a distinctive manner of imagining the real', to use the words of anthropologist Clifford Geertz.[81] Interestingly, this function of law in symbolizing, imagining, and representing the world around us gains special significance within the context of biolaw. After all, biomedical technologies are blurring, as mentioned, the distinctions between foundational categories, such as subject and object, life and death, and animal and human. As existing vocabularies seem to be falling short of making sense of biomedical developments, legal discourse is stepping in to contribute to the creation of an *imaginaire social* to symbolize these new biomedical hybrids. Without doubt, other systems of meaning profoundly affect the legal process of symbolization, such as medical, religious, and economic perspectives. However, when the symbolic orders of these systems collide, as is mostly the case in bioethical matters, law has to mediate between these competing systems of value and meaning. Under these circumstances of symbolic uncertainty, the law, with its intricate systems of multiple and inter-related terms, qualifications, constructions, and categories, can become of vital importance to the overall cultural-symbolic process to come to terms with technological hybrids.[82]

The same could be argued in relation to the new status questions raised by human genetic engineering. What should we make of the 'three parent babies' of mitochondrial replacement? Should women who donate their egg cells for this procedure be recognized as a second legal mother? And in the likely case that the law answers this question in the negative, should her genetic ties with the child, even if they are quite minimal, be reflected in other ways in family law? Even if these questions seem almost impossible to answer, the law will nevertheless have to come up with solutions.

What about the designer babies of human gene-editing? The confounding complexity of the questions which are raised by human genetic engineering can be illustrated by the emergence of wrongful life claims from children who are born out of new technological settings. In the future, the law will without a doubt also be faced with wrongful life claims from children in case of mistakes which are made during the process of human gene-editing, or in case these children would rather have been born with a different genetic profile. Can they sue their makers or designers for these 'defects'? Can they claim the right to be born with a different genetic profile, or even in a different body? And if so, what does that mean for law's concept of the person? While coming to an answer to these immensely difficult questions, judges will inevitably have to draw up new lines between person and thing, artifice and nature, and chance and choice.

[81] C Geertz, 'Local Knowledge. Fact and Law in Comparative Perspective' in C Geertz, *Local Knowledge. Further Essays in Interpretive Anthropology* (Basic Books 1983) 184.

[82] Elsewhere, I have analysed law's special role in the general process of cultural-symbolic representation of biomedical hybrid objects more elaborately. See BC van Beers, 'From Winged Lions to Frozen Embryos, Neomorts and Human-Animal Cybrids: The Functions of Law in the Symbolic Mediation of Biomedical Hybrids' in B van Klink et al (eds), *Symbolic Legislation and Developments in Biomedical Law* (Springer 2016).

Additionally, the symbolic perspective on technological interventions is also able to make sense of the feelings of moral vertigo and the emotions of revulsion, to which Sandel, Habermas, and Jonas refer when they discuss the impact of technological developments on existing normative frameworks. These feelings and emotions could be regarded as an indication of the radical ways in which emerging technologies question existing cultural-symbolic categories. However, as mere indications of the radical impact of technological interventions, these feelings and emotions cannot replace legal and ethical arguments, as already argued.

One can wonder whether law is up to this task of imagining future biomedical realities and countering the symbolic uncertainties caused by biomedical hybrids. However, the fact is that law is already called upon to answer the semi-metaphysical questions raised by technological developments, even if law is perhaps not the most likely or best equipped candidate to do so. Decisions from European courts on the meaning of human dignity for technological regulation can serve as illustrations.[83] These decisions attest to the fact that even if the risks involved in biomedical developments are rather of a metaphysical than a physical nature, this does not preclude the possibility of a gradual process of legal symbolization, in which existing foundational categories can be reconstructed and reconsidered along the way. It could be said that in this process, law makers and judges are unfolding, what Bruno Latour has called, an *experimental metaphysics*.[84] Applied to law, the perspective of experimental metaphysics can be taken to mean that the categorical distinctions between human and animal, alive and dead, and person and thing, which are each being uprooted by biomedical technologies, can be renegotiated in international biolaw through a continuous, case-by-case, and therefore experimental approach, in which different symbolizations and representations of the human gradually take shape.

7.5 Conclusion

Imagining the future; that is what scientists are currently doing by creating new futures and even new modes of human existence. If that is the case, lawyers cannot but join them in this effort of the imagination if societies want to offer some direction for these essentially political and ethical questions. Drawing from Jonas's normative framework for utopian technologies, this chapter has argued that legal imagination is primarily involved on two levels.

First, as the long-term consequences of biomedical technologies, such as human genetic engineering, are unknown yet potentially catastrophic for human evolution or human existence, law makers are called upon to give priority to the negative over

[83] See, eg, on IVF and gamete donation: *Evans v United Kingdom* [GC] No 6339/05 (Grand Chamber, 10 April 2007); *SH v Austria* No 57813/00 [GC] (Grand Chamber, 3 November 2011); on organ donation: *Elberte v Latvia* No 61243/08 (Fourth Section, 13 January 2015); and on the use of embryos for industrial or commercial purposes: Case C-34/10 *Brüstle v Greenpeace eV* [2011] ECR I-09821.

[84] B Latour, *Politiques de la Nature. Comment Faire Entrer les Sciences en Démocratie* (La Découverte 2004) 97.

the positive prognosis. This strategy is clearly visible in precautionary regulatory approaches. From that perspective, there is a legitimate place for dystopian ways of thinking and imagining in biolegal discourse.

Second, human genetic engineering and other human enhancement technologies bring about uncertainties and risks also on a more conceptual level. Much of the controversy surrounding these emerging technologies is due to the fact that categorical distinctions, such as between person and thing, and chance and choice, are blurred in radical ways. As a consequence, the emergence of biomedical technologies also entails what could be called metaphysical risks and symbolic uncertainties. How should we come to an understanding of three-parent embryos, gene-edited children, or human–animal cybrids? Indeed, all of these biomedical 'hybrids' seem to surpass existing foundational categories. Interestingly, the law is becoming of increasing importance in the social-cultural process of imagining and evaluating possible new creations. Also in this sense, law's imaginative powers are increasingly mobilized to regulate and represent the new realities which may be called into existence by emerging technologies.